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An Exploration of Close Relatives' Experience of Help-Seeking for Dementia.

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A Review of the Literature

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Summary of Portfolio

Section A is a review of the literature on help-seeking and dementia. The review begins with an introduction to the topic of dementia and help-seeking, providing an explanation of psychological theory that has been used in this area. The review highlights methodological limitations and gaps in the literature, providing a rationale for future research.

Section B is a qualitative study exploring close relatives' experience of help-seeking for dementia. Interpretative Phenomenological Analysis was used to analyse interview data from nine participants. Three themes emerged from the analysis, depicting the help-seeking process: (1.) developing the courage to act (2.) naming the elephant in the room and (3.) repositioning. The results are discussed in the context of the existing literature and consideration is given to future research directions.

Section C is a critical appraisal of the qualitative project 'An Exploration of Close Relatives Experience of Help-Seeking for Dementia'. It provides critical and reflective answers to four questions: (1.) What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further? (2.) If you were able to do this project again, what would you do differently and why? (3.) Clinically, as a consequence of doing this study, would you do anything differently and why? (4.) If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?

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Section A:

**Help-Seeking in Dementia: A Review of the
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Abstract

UK policy emphasises the importance of early diagnosis and intervention in dementia care. However, most people with dementia do not seek help when they first notice symptoms. These findings demonstrate the need for a clearer understanding of help-seeking for dementia. This review introduces the topic area of dementia and help-seeking and provides an explanation of theory that has been used in this area, namely the Common Sense Model of Illness Representations (CSM). A critique is provided, identifying limitations and gaps in the literature. Specific consideration is given to the importance of close relatives in the process of recognising the first signs of dementia and seeking help. Consideration is also given to the value of the CSM in explaining how people conceptualise dementia and make decisions to seek help. The review concludes with a rationale for future research.

Introduction

It is estimated that 800,000 people in the UK are living with dementia (Alzheimer's Society, 2012), a figure that is predicted to rise to 1.7 million by 2050, due to the ageing population in the UK (National Audit Office, 2010). There is a growing body of research, which supports early diagnosis and intervention as a way of enhancing the psychological and social wellbeing of people with dementia and their families (Scott & Donnelly, 2005). However, it is estimated that only 43% of people with dementia in the UK have a diagnosis (Alzheimer's Society, 2012) with many seeking professional help at a late stage where interventions such as cognitive stimulation therapy and drug treatments may be less effective (Banerjee & Chan, 2008; Milne, 2010). For these reasons it is important that a better understanding of what motivates people to seek help and intervention is gained.

This review introduces the topic of dementia and help seeking, followed by a focused review of the empirical and theoretical literature and consideration of the utility of current psychological theory, namely the Common Sense Model of Illness Representations (CSM) (Leventhal, Meyer, & Nerenz, 1980), in exploring help-seeking behaviours. The review concludes by highlighting gaps in the current literature and presenting a rationale for future research into help-seeking for dementia.

The review literature was identified using a series of online databases (PsychInfo, Web of Knowledge, Medline and Cochrane). In total 13 publications were reviewed: 10 empirical and three review or discussion papers. A full account of the search strategy used to identify the literature and results can be found in Appendix A. Additional publications have been referenced where relevant.

What is Dementia?

Dementia is used as an umbrella term to describe a collection of symptoms including memory loss, mood changes and problems with communication and reasoning. Symptoms are a consequence of progressive degeneration of cells in the brain (Nuffield Council on Bioethics, 2009). There are over 100 different types of dementia. Some of the most common are Alzheimer's disease (accounting for over 62% of all dementias), vascular dementia (17%) and mixed dementia (10%). Less common types include dementia with Lewy bodies (4%) and fronto-temporal dementia (2%) (Alzheimer's Society, 2010).

Alzheimer's disease is often understood as occurring in three stages. During the early (or mild) stage, symptoms include forgetfulness, difficulty making decisions and confusion; during the middle (moderate) stage symptoms include deeper confusion, loss of short-term memory; and then the later (severe) stage is where symptoms can include incontinence and aggression. The symptoms exhibited and progression of dementia are dependent upon a number of different factors including the underlying condition, the specific regions of the brain that are affected, the physical health of the person and the individual themselves. There is considerable individual variation in symptoms and speed of deterioration (National Institute of Clinical Excellence NICE, 2010).

The chances of developing dementia, particularly Alzheimer's disease, increase with age, therefore with the ageing population in the UK, dementia is "one of the most important public health issues of our generation" (Nuffield Council on Bioethics, 2009). Whilst some changes in the ability to think (e.g. occasional forgetfulness) are considered to be part of the normal ageing process, dementia is not a normal outcome of ageing (Retirement Unlimited, 2009). People who have dementia are often not aware of

occasions when they have forgotten information, and their difficulties are progressive, having an increasing effect on their ability to perform activities of daily living.

Mild Cognitive Impairment (MCI) is another, more recent term, which is often associated with dementia. MCI is a descriptive term used to describe people who have subjective memory problems, supported by neuropsychological testing, without the presence of other dementia symptoms (Alzheimer's Society, 2010). Research into MCI suggests that it can indicate people who are in the early stages of dementia; however, MCI can also be the result of stress, depression, anxiety and physical illness, for these reasons MCI is not synonymous with a diagnosis of dementia. Research which has focused upon MCI, rather than dementia, is not included as part of this review.

A Biopsychosocial Model of Dementia

As noted above the symptoms of dementia vary hugely from person to person making it hard to define a 'typical' dementia profile (Sabat, 2001). In respect of this it is helpful to take a biopsychosocial stance, viewing the health, well being and quality of life of an individual as an interplay between biological, psychological and social factors (Engel, 1977). Within the dementia literature, Kitwood (1997) has proposed a holistic framework where dementia is viewed in terms of the person's neurological impairment, psychological responses and the social context in which they are situated. This framework supports the idea that a positive and compassionate social environment will slow down the progression of dementia and help to maintain the person with dementia's sense of 'personhood'¹ (Kitwood, 1997).

Managing a chronic condition such as dementia requires flexibility and constant adjustment by those affected (Holman & Lorig, 2000), including family and carers.

¹ Personhood: Kitwood (1997) claimed that personhood was sacred and unique and that every person had an ethical status and should be treated with deep respect.

Based on Kitwood's framework, Clare, Rowlands and Quin (2008) propose a holistic approach to treatment with: physical care and pharmaceutical treatment offered at a biological level, therapeutic and psychological intervention to facilitate education and support for carers. In a review of the literature on treatment and intervention, Milne (2010) suggests that it is intervention at an early stage which may be most critical, offering the opportunity to make changes that have a positive effect upon the quality of life of the person with dementia and their family.

Intervention and Early Diagnosis

In the UK, the Prime minister recently announced the launch of a new programme of work called *Challenge on Dementia* (Department of Health, 2012), which aims to improve dementia care and research by 2015. This programme is aimed to build upon the work of the Department of Health's *National Service Framework (NSF) for Older People* (Department of Health, 2001) and the more recent *Living Well with Dementia: A National Dementia Strategy (NDS)* (Department of Health, 2009). The NSF and NDS made it a key aim for services for older people and memory clinics to improve early diagnosis and intervention. This call is prompted by reports from clinicians and researchers that caregivers often missed the early symptoms of dementia (Werner, 2003) or sought help at a point of crisis or the advanced stages of the condition (Boise, Camiciia, Morgan, Rose, & Congleton, 1999). The medical profession often considers diagnosis in the advanced stages of dementia to have less value, because pharmaceutical interventions have limited effect at this stage. For the person with dementia and their family, intervention and diagnosis at any stage is likely to be really important in terms of accessing care and support.

The aim of early diagnosis and intervention is to maintain independence for as

long as possible for the individual diagnosed, as well as improving quality of life for the person and their family (Mittelman, Roth, Clay, & Haley, 2007). Early diagnosis is thought to enable the person to understand what is wrong with them (Elson, 2006) and allow them to plan for future care needs (Woods & Pratt, 2005), including financial and legal provisions, for example, making a will and lasting power of attorney (Milne & Wilkinson, 2002). Diagnosis also provides access to treatment interventions including: cognitive stimulation therapy, reminiscence therapy (Woods et al., 2009), pharmacological interventions (e.g. cholinesterase inhibitors) (Boise et al., 1999) and support for relatives (Banerjee et al., 2007). These benefits have also been linked to a delay in care home admission (Mittelman et al., 2007).

Despite the potential advantages of diagnosis and early intervention, it is important and reasonable to consider that not all people with dementia and their families want diagnosis and intervention. To respect patient choice, health professionals need to respond to individual preferences, including decisions not to seek a diagnosis or particular intervention (Bamford et al., 2004). It is possible that early intervention may increase anxiety and levels of depression (Carpenter et al., 2008) and in the same vein as those who may want to know what is happening to them, there are going to be those who do not want to know. Clare, Goater and Woods (2006) describe how people with dementia and their family may engage in what they call “defensive denial” (p.765) as a means of coping and protecting their psychological wellbeing (Weinstein, Friedland, & Wagner, 1994) and Whitehouse and Juengst (2001) argue that health professionals are driven towards medicalising the ageing process and over using labels such as MCI and Alzheimer’s disease. Further, Milne (2010) suggests that people with dementia and their relatives may consciously seek to avoid being diagnosed or “problematized” (p.11) as they wish to resist being included in the medical sphere of influence and the reach of

power held by health professionals. Whilst health professionals construct avoidance of medical intervention as “denial”, for people with dementia and their family it may be a robust method of coping with difficult or uncomfortable news.

Regardless of whether people choose to seek help or not it is important for services to have an understanding of the factors that influence peoples’ decisions about intervention and diagnosis.

Help-Seeking

Help-seeking is a term used to encapsulate behaviour or action taken when physical, cognitive and psychological changes and symptoms are noticed. It is not limited to decisions surrounding seeking a diagnosis but is a complex process of identifying, interpreting and responding to cognitive or behavioural changes (Mechanic, 1968). In a concept analysis, Cornally and McCarthy (2010) defined help-seeking behaviour as “the intentional action to solve a problem that challenges personal abilities” (p.13).

Help-seeking is intrinsically linked to coping and is one of the first steps in the coping process as individuals assess their health status. Lazarus and Folkman (1984) describe this process in their transactional model (TM) of coping where a person’s response to stress (signs and symptoms of the condition, in the case of dementia) is affected by the person’s appraisal of the stressor and the social and cultural resources they have at their disposal. As mentioned above, there can be a huge variation in peoples’ responses to a threat to health like dementia, such as seeking information, engaging in therapeutic or medical interventions or defensively denying knowledge of the problem (Weinstein et al., 1994). In line with the TM, Ursin and Eriksen (2004) propose that this variability in how people respond to a threat to health is related to

expected outcomes, and the individual's available resources.

Help-Seeking for Dementia

Research that has begun to explore the area of help-seeking has focused heavily upon barriers to diagnosis (Krull, 2005; Speechly, Bridges-Webb, & Passmore, 2008), rather than looking at help-seeking more broadly. Van Vliet et al. (2011) conducted a qualitative study in the Netherlands investigating caregivers' perspectives on recognising and diagnosing early onset dementia (onset before 65 years). Results from 92 interviews with caregivers revealed a series of barriers to people seeking help including: refusal to seek help, faulty diagnoses, denial and professionals inadequate help. These results are similar to those found by Mukadam, Cooper and Livingstone (2011) in a systemic review of black and minority ethnic (BME) pathways to dementia diagnosis. They also identified additional barriers for BME people including: not conceptualising dementia as an illness, experiences of shame and stigma within the community, and negative experiences of healthcare services. This research provides a clear indication of some of the barriers to seeking a diagnosis but lacks an in depth understanding of how people negotiate and initiate the process between noticing signs and symptoms of dementia and seeking support and advice.

Cognitive Social Learning Theory

One way to try and understand help-seeking behaviours is to draw upon cognitive social learning theory, which proposes that whilst our behaviours are influenced by reinforcements (e.g. reward), they are also dependent on what we observe of others and social or cultural norms (Bandura, 1997). This links to the importance of those in our social environment, particularly relationships with relatives

where there is greater emotional intensity. Where the first signs and symptoms of a condition are noticed, Zola (1973) describes how the role of relatives is often one of sanctioning that seeking help is required or justified, and friends, family, colleagues and neighbours are often the people who are turned to first (Friedson, 1961). Cameron, Leventhal and Leventhal (1993) have also demonstrated that it is the lay network (usually family and friends) who become involved in decisions over whether to seek professional advice and support.

The Lay Network

To try and gain an understanding of the patterns and predictors of help-seeking, Hodgson and Cutler (2004) conducted a survey-based investigation with adults aged 40-60 years with personal concerns about dementia. Results showed that respondents who were concerned about developing dementia were most likely to take their concerns and fears to their lay network. Although this research did not involve people with a diagnosis of dementia it highlighted the key role that friends and family play in decisions about whether to seek help.

For dementia, the role of relatives may be particularly important for identifying the first signs and symptoms, where the person with dementia may not always have insight into their cognitive changes and symptoms (Green, Mohs, Schmeidler, Aryan, & Davis, 1993). For example, awareness of difficulties can be limited because of cognitive changes limiting the ability to self-monitor and evaluate (Morris & Hannesdottir, 2004).

Hodgson and Cutler's (2004) research, and what is known from cognitive social learning theory, indicate the importance of exploring family members' experiences of seeking help for dementia to gain an understanding of their role. So far, there has been little research in the UK that has focused upon this area. In an Australian study,

Robinson et al. (2009), undertook a questionnaire based study looking at family carers' experiences of help-seeking (seeking information and services) for dementia. They concluded that family members took a very active role in seeking help and diagnosis, and that there was a need for health professionals and service providers to "seriously" and "empathically" (p.10) acknowledge and react to family members' requests for information and a speedy diagnosis. Two qualitative interview based studies, one by Teel and Carson (2003) with family caregivers, and the other by Iliffe and Wilcock (2005) with GP's and specialists, also reported that family carers eagerly sought information about diagnosis and dementia.

The findings from these studies demonstrate the involvement of family members in the process of seeking help. If services are to develop the support and information that they provide for family members, they will require a clearer understanding of the process of problem-recognition and the factors that initiate help-seeking.

One study that has sought to expand the current knowledge base is a Canadian study by Leung et al. (2011) investigating the experiences of problem recognition and seeking help for individuals with early onset dementia and their primary carers. The study used an inductive thematic approach to analyse semi-structured interviews conducted with six people with a diagnosis of dementia and their carers. Five major themes were identified: becoming aware of memory problems, attributing meanings to symptoms, initiating help-seeking, acknowledging the severity of cognitive changes and finally obtaining a definitive diagnosis.

The findings presented are helpful for providing a detailed chronology of the events proceeding diagnosis. However, similar to the wider help-seeking literature, the study lacks consideration of a theoretical framework. Research that draws upon theory

is key for the creation of an evidence base and for facilitating the planning, commissioning and implementation of interventions (Green, 2000).

Models of Understanding

The review will now consider models of understanding that are applicable to the process of help-seeking.

A number of different models for understanding individuals' differential responses to difficulties with their health (e.g. help seeking, medication adherence and coping) have been proposed within the health psychology literature. Some of the most widely applied models for understanding peoples' responses to health include: the Health Belief Model (HBM) (Becker, 1974), Theory of Planned Behaviour (TPB) (Ajzen & Madden, 1986) and the Common Sense Model of illness (CSM) (Leventhal, Meyer, & Nerenz, 1980). It is the CSM that has been applied most widely in the area of dementia and a more detailed consideration follows.

The Common Sense Model of Illness Representations (CSM)

The theoretical underpinnings of the CSM, which is also known as the Self-Regulation Model (SRM), are based upon self-regulation theory. The theory views people as active problem solvers who, when faced with a difficulty such as a health problem, are motivated to engage in a process of gathering relevant information (e.g. speaking to friends, family or health professionals). The information is integrated with previous knowledge to form an assessment of current health status and this assessment acts as a feedback system, informing future coping efforts (Benyamini, 2009). This suggests that people with chronic conditions, like dementia, are involved in a constant process of monitoring, adjusting and evaluating their coping strategies.

The CSM (Leventhal et al., 1980) seeks to explain how people develop their own personal model of illness (an illness representation). Illness representations are thought to conceptualise a person's beliefs and expectations about an illness or somatic symptom (Diefenbach, 1996). Illness representations have been described by researchers in a series of different ways including illness cognitions (Rutter & Rutter, 2002), illness perceptions (Weinman, Petrie, Moss-Morris, & Horne, 1996) and patient schemata (Pennebaker, 1982). For the purposes of this review the term illness representation is used.

The model proposes that when trying to make sense of a threat to health, people form both cognitive representations and emotional responses to the illness. To try and self regulate, it is thought that efforts to try and manage these cognitions and emotions are made. These are the "common sense" coping behaviours that people engage in (e.g. going to the GP, taking medication). Finally the model suggests that the effectiveness of coping strategies is appraised, which influences cognitive and emotional representations and governs future coping methods (Leventhal, Brisette, & Leventhal, 2003). Due to the fact that coping is thought to be both determined by and appraised in relation to illness representations, coping is seen to have a mediating role between an individual's illness representation and their well-being.

The CSM is called a parallel processing model because people are believed to form both cognitive and emotional representations of the illness, which means that their response to a health threat like dementia might be triggered by either an emotional or cognitive process. The cognitive representations that people form are thought to encompass five components, demonstrated consistently by the research (Meyer, Levetthal, & Gutmann, 1985; Lau, Bernard, & Hartman, 1989). The five components include the person's beliefs about the identity of the health threat, the

cause and consequences, prognosis or time line and the degree of controllability. It is along these 5 dimensions that beliefs about an illness may vary (Hamilton-West, Milne, Chenery, & Tilbrook. 2010), meaning that representations are specific to the individual. The CSM proposes that it is people's illness representations that are of greatest importance for providing insights and enhancing understanding of help-seeking.

Not all researchers are agreed on the utility of illness representations as presented in the CSM. For example, Heijmans (1999) contends that categories of illness representations specific to each illness should be generated. Nevertheless, Hagger and Orbell (2003) advocate for the use of the five dimensions as they are based upon extensive research. The CSM's strengths are that it is a model which can be applied to specific illnesses, which has been demonstrated across a series of different health conditions including cancer (Kelly et al., 2005), chronic fatigue syndrome (Heijmans & De Ridder, 1998), diabetes (Skinner et al., 2006), severe mental illness (Lobban & Barrowclough, 2005) and to a limited degree, dementia (Harman & Clare, 2006).

Reviewing the Evidence on the CSM and Dementia

To date, there are few studies that have drawn upon the CSM in the investigation of coping and help seeking for dementia. Existing research has tended to focus on people who are in the early stages of a dementia diagnosis.

Clare, Goater and Woods (2006) carried out semi-structured interviews with 22 people diagnosed with Alzheimer's disease or mixed dementia to investigate the illness representations held by people in the early stages of dementia. Additional information about the participant's mood was collected using the Hospital Anxiety and Depression Scale (HADS) (Snaith & Zigmond, 1994) and interview transcripts were analysed using a

qualitative content analysis where the 5 dimensions of the CSM (Leventhal et al., 1980) were used to code.

The results of the study showed that participants' representations covered the five dimensions of the CSM (identity, cause, course, control & consequences). However, the illness representations held by participants deviated from professional constructs in some important ways. For example, the majority of participants described their difficulties as "part of normal ageing" (p.1) and one-third of participants described the dementia as "stable or improving" (p.1). This is in line with research looking at other health conditions where an "illness ageing rule" has been demonstrated, where people attribute milder health related symptoms to the ageing process (Leventhal et al., 1997). This is an important finding in relation to the process of help-seeking as studies focused on other age related conditions, such as urinary incontinence, have found that where participants attributed symptoms to normal ageing it delayed seeking help or advice (Locher, Burgio, Goode, Roth, & Rodriguez, 2002). Clare et al.'s (2006) results also showed that where participants believed nothing could be done to help them, they were more likely to demonstrate higher levels of psychological distress (scoring above the clinical cut off for depression and anxiety). The results suggest that the illness representations people with dementia hold are likely to affect their psychological wellbeing. This is likely to impact upon people's decisions to seek help as they may be less likely to seek help where they believe that little can be done.

Clare et al. (2006) describe how both the interview schedule and deductive form of content analysis used were based upon the five dimensions of the CSM. This is a major limitation of the research because, despite the use of a semi-structured interview schedule, participant responses were likely to be limited to discussing the five dimensions of the CSM. This is at odds with the aim of qualitative content analysis,

which seeks to attend to unique themes and meanings as opposed to the occurrence of particular concepts (Zhang & Wildemuth, 2009). Had the authors adopted a research methodology such as Interpretative Phenomenological Analysis (IPA) (Smith, Jarman, & Osbourne, 1999) it would have allowed a more exploratory analysis of the data.

Clare et al. (2006) acknowledged that psychosocial factors such as society's view about dementia and the stigma associated with the diagnosis were likely to influence the illness beliefs held by participants, prompting the authors to suggest that further research exploring the illness representations held by carers and relatives should be conducted.

Harman and Clare (2006) expanded upon Clare et al. 's (2006) study, conducting an exploratory qualitative study using IPA. The illness representations of nine participants, diagnosed as being in the early stages of dementia, were explored using semi-structured interviews. The aim of the study was to see how participants' illness representations were related to daily-lived experience.

Results from the study indicated two overarching themes: "It will get worse" and "I want to be me" (p. 496), Harman and Clare (2006) proposed that the themes demonstrated participants' efforts to try and acknowledge the prognosis of their condition, whilst trying to maintain their self identity. The authors used the data to formulate a tentative model of the relationship whereby participants' illness representations were seen as informing their strategies for managing symptoms, as well as combining with their lived experience to help them to maintain a sense of self during the dementia related changes. In line with the CSM, the model proposed suggests that illness representations underpin the differential response and adaptations exhibited by people who receive a diagnosis of dementia.

Harman and Clare (2006) noted a number of interpersonal and personal dilemmas faced by participants. Dilemmas included the difficulty arising between the person with dementia and their social network, regarding how they wished to be viewed (with regard to their roles and relationships) within their family and how they wanted their lay network to view them. The study did not discuss what impact these dilemmas may have had upon decisions to seek help. Through speaking to people who have had their diagnosis for longer or conducting longitudinal research, it would be possible to gain an understanding of the impact that these dilemmas have upon decisions to seek help and to find out whether such dilemmas are ever resolved. Further research might also consider the illness representations held by relatives to gain an understanding of how these differ or converge with that of the person with dementia.

To date, only one study has focused upon the illness representations of the lay network (friends and family). Hamilton-West, Milne, Chenery and Tilbrook (2010) conducted a pilot study to investigate the potential utility of the CSM for understanding lay perceptions of dementia, and predicting intentions to seek help based on possible signs and symptoms. They used a vignette based study where participating undergraduate students were presented with a vignette describing a person with mild or moderate dementia and asked to imagine that this person was a relative. Following the presentation of the vignette, participants completed a series of questionnaires, measuring their illness representations and intentions to seek help.

The results indicated that lay participants were more likely to recognise cognitive deficits as being related to dementia and that non-cognitive signs and symptoms were attributed to psychological causes such as stress or depression. Participants were more likely to indicate an intention to seek help from professionals where they identified the signs and symptoms in the vignette as dementia and when

they perceived symptoms as severe, having serious consequences and as likely to be permanent. Participants were less likely to seek professional help when they had identified the case in the vignette as stress or symptoms attributable to a psychological cause. The authors concluded that 'help seeking may be prevented by inaccurate illness representations or misattribution of symptoms' and that it would be important for future research to investigate 'the extent to which intentions to seek help translate into actual help seeking on behalf of a relative with dementia' (p. 9). The CSM was believed to provide a helpful framework for understanding how participants made sense of dementia symptoms. The authors proposed that the CSM might prove to be a useful model for informing help-seeking pathways.

Limitations identified within the study included the use of a convenience sample of young predominantly female undergraduate students. Recommendations were made for further research to be conducted with a sample more representative of the wider population. Whilst replicating this study with a sample representative of the wider population would provide information regarding the lay population, future research might also look to draw on the experiences of relatives and friends of people who have received a diagnosis of dementia to explore their role in the process of seeking help, for example, exploring their illness representations and how the recognition of signs and symptoms of dementia triggered or informed decisions to seek help.

Hamilton-West et al. (2010) used self-report measures to investigate participants' illness representations and help-seeking intentions. Although this allowed the authors to collect data from a large participant sample ($N= 118$) the use of questionnaires to measure these variables raises questions about the construct validity of the self-report measures (Kaplan, 1996) and risks mono-method bias. Future research might look to avoid such limitations through the use of qualitative research

methods (e.g. interview based study) or adopting a mixed methods design (using interviews and questionnaires).

Summary

The review of the wider dementia literature highlighted the importance of continued research into help seeking, given the existing evidence that intervention at an early stage in the dementia process can offer improved opportunity for planning and making changes that have an impact upon a persons quality of life (Milne, 2010; Milne & Peet, 2008) both physically and psychologically.

Not all people who notice dementia-related symptoms choose to seek help and there is a need to better understand how people make sense of their symptoms and make decisions about whether to seek help. Where help-seeking is initiated the research suggests (Hodgson & Cutler, 2004) that the lay network may play an integral part in the context of providing support and sanctioning decisions to seek professional help.

To date much of the research has focused upon barriers to diagnosis rather than considering help-seeking more broadly. There has been little attempt to explore and understand how people move from a position of noticing symptoms to one of seeking advice and information.

A limitation of current research was the lack of a theoretical basis, although there is an emerging research base, indicating that the CSM (Leventhal et al., 1980) may provide a helpful framework for understanding how people form personal representations of dementia (Clare et al., 2006; Harman & Clare, 2006; Hamilton-West et al., 2010). Research into the CSM so far, indicates that the illness representations that people held about dementia were linked to how well people coped with their condition

psychologically and practically (Clare et al., 2006; Harman & Clare, 2000) as well as decisions about whether to seek help (Hamilton-West, 2011). Research is yet to explore the illness representations held by close relatives and those in the social network of the person with dementia.

Further research into help-seeking and dementia is necessary and warranted given the important implications it would have for dementia services, for example, in how interventions and health campaigns for dementia are targeted.

Rationale for future research

The gaps in the current research base are considered below, with suggestions for future research directions.

The review has highlighted the need for further research into help-seeking and dementia, with the aim of understanding the process that people go through when they shift from a position of noticing symptoms to one of taking action, research so far has tended to focus upon barriers to diagnosis. People with dementia are often described as being in a state of denial (Clare et al., 2006). However, little is known about whether denial is a static state (where people continue to deny their difficulties) or if people move to a position of being ready to acknowledge and accept their difficulties.

Due to the integral part that the lay network play in help-seeking, the review has also stressed the importance of exploring the experiences and illness representations of close relatives to better understand their involvement in identifying symptoms and prompting help-seeking. Qualitative research involving close relatives of people who have been given a diagnosis of dementia would build on the work of Hamilton-West et al. (2010) through looking at how noticing signs and symptoms of dementia translated into actions to seek help. A qualitative research methodology such as IPA might be a

suitable approach, as it would allow participants the flexibility to discuss and put forwards their own experiences. Longitudinal research would also provide rich information surrounding experiences of symptom recognition and help-seeking.

Another area that future research could focus upon would be to investigate the relationship between illness representations and levels of psychological distress further. Clare et al. 's (2006) study showed a link between the illness representations that people with dementia held and the level of psychological distress they experienced. These results would need to be replicated on a much larger scale, using quantitative research methods for the results to be generalisable.

Conclusion

The review set out to investigate the current empirical and theoretical literature surrounding help-seeking and dementia. The literature highlighted how help-seeking for dementia is a key area for further research due to the benefits of seeking support and intervention at an early stage for the person with dementia and their family. The research indicated that help-seeking is a joint endeavour between the person with dementia and their family. Currently, little is known about close relatives' experiences of help-seeking and further research is necessary to shed light upon the role of relatives in the recognition of dementia symptoms and decisions to seek help.

There is a growing body of evidence that suggests that the common sense model of illness representations may provide a useful framework for conceptualising how people with dementia make decisions about coping and seeking help. This is another area where further research is necessary to confirm a link between illness representations and help seeking.

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Section A

Appendix A

Literature Search Strategy

The following databases were searched up until April 2012: PsycInfo, Web of Knowledge, Medline and Cochrane.

The search terms used included: Dementia OR Alzheimer's Disease And Common Sense Model of Illness Representations OR Health Belief Model OR Illness Representations OR Health Beliefs OR Self Regulation Theory OR Patient Schemata OR Theory of Planned Behaviour OR Illness Perceptions OR Illness Beliefs OR Illness Cognitions.

The results for each of the different search terms can be found in Table 1 below.

The researcher scanned through the papers returned for each search to identify papers relevant to the review topic. Due to the lack of research in this area, papers were selected for their relevance to the review topic rather than for their methodological quality.

Table 1*Search Results*

| Search terms used | Papers returned | Papers identified for review |
|--|------------------------|--|
| Dementia Or Alzhiemer's Disease And Common Sense Model of Illness Representations. | 1 | 1 – Hamilton-West, Milne, Chenery and Tilbrook (2010). |
| Dementia Or Alzhiemer's Disease And Health Belief Model. | 15 | 2 - Leung et al. (2011) and Van-Vliet et al. (2011) |
| Dementia Or Alzhiemer's Disease And Illness Representations. | 21 | 2 – Clare, Goater & Woods (2006) and Harman and Clare (2006). |
| Dementia Or Alzhiemer's Disease And Health Beliefs. | 130 | 3 – Iliffe and Wilcock (2005), Hodgson and Cutler (2004) and Robinson et al. (2009). |
| Dementia Or Alzhiemer's Disease And Self Regulation Theory. | 7 | 0 |
| Dementia Or Alzhiemer's | | |

| | | |
|--|----|--|
| Disease And Patient Schemata. | 1 | 0 |
| Dementia Or Alzheimer's Disease And Theory of Planned Behaviour. | 2 | 0 |
| Dementia Or Alzheimer's Disease And Illness Perceptions. | 90 | 1- Teel and Carson (2003) |
| Dementia Or Alzheimer's Disease And Illness Beliefs. | 49 | 2- Mukadam, Cooper & Livingstone (2011) and Speechly, Bridges-Webb & Passmore (2008) |
| Dementia Or Alzheimer's Disease And Illness Cognitions. | 8 | 0 |
| Dementia Or Alzheimer's Disease And Help-Seeking. | 91 | 2- Krull (2005) and Cornally and McCarthy (2010) |

Section B:

An Exploration of Close Relatives' Experience of Help-Seeking for Dementia

Word Count: 7803

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Abstract

A qualitative investigation was conducted to explore close relatives' experiences of symptom recognition and help-seeking for dementia. Nine participants took part in a one-to-one interview. The interviews were semi-structured and aimed to address the following topics: symptom recognition and the process of seeking information and support. Interview transcripts were analysed using interpretative phenomenological analysis (IPA). Three superordinate themes emerged from the analysis: 'Developing the courage to act', 'Naming the elephant in the room' and 'Repositioning'. Findings highlighted how participants' shifted from a position of having unspoken fears about their relatives' symptoms to a point where they were able to address these fears and help their family member to seek help. Participants were engaged in developing representations of dementia, in line with research on the common sense model of illness representations (CSM). The findings highlighted potential areas of improvement for dementia services in the UK, including the provision of greater support for close relatives (e.g. psychological assessment and intervention). Further research, on a larger scale, is needed to determine whether the CSM provides a useful framework for understanding help-seeking for dementia.

Introduction

Dementia is a term used to describe a collection of symptoms that include loss of memory, confusion, mood changes and problems with speech and understanding (Alzheimer's Society, 2012; Department of Health, 2007). The symptoms are a consequence of progressive degeneration of cells in the brain (Nuffield Council on Bioethics, 2010), which in the longer term can result in difficulties performing the activities of daily living and loss of independent functioning (DoH, 2009). There is considerable individual variation in symptoms and speed of deterioration. Some of the variation is dependent on factors such as the underlying condition, the regions of the brain affected, physical health, emotional resilience and support available. It is estimated that there are 800,000 people living with dementia in the UK, a figure that is set to rise to over a million by 2021 (Alzheimer's Society, 2012). The most common types of dementia include Alzheimer's disease (accounting for over 62% of all dementias), vascular dementia (17%) and mixed dementia (10%) (Alzheimer's Society, 2012).

Although dementia symptoms vary considerably it is often understood as occurring in three stages: during the early ("mild") stage minor changes in memory and comprehension are common; in the middle ("moderate") stage, increasingly forgetful and confused behaviours occur; and in the late ("severe") stage symptoms can include incontinence or aggression. Critically, it is the early stages of dementia where there is opportunity for interventions that may have an effect on the quality of life of the person with dementia and their family (Milne, 2010). Interventions can include the implementation of support strategies that will help the person maintain their independence (Alzheimer's Society, 2010), plan for future care needs (Woods & Pratt, 2005) and make financial and legal plans (e.g. lasting power of attorney) (Milne &

Wilkinson, 2002). Early diagnosis and intervention are key aims of the Department of Health's (DoH) National Dementia Strategy (NDS) (DoH, 2009).

In spite of the growing support for early diagnosis it is estimated that only 43% of people with dementia in the UK have a diagnosis (Alzheimer's Society, 2012). The symptoms of dementia are often missed or attributed to other causes (e.g. ageing, anxiety and depression) and where help is sought it can often be at the advanced stages of the condition (Boise, Camicioli, Morgan, Rose & Congleton, 1999) where less can be done to support the individual and their family. A better understanding of how people with dementia and their families move from a position of noticing symptoms to seeking help will help to develop current services and resources further.

An Overview and Critique of the Literature on Help-Seeking and Dementia

Help-seeking can be defined as the action taken to resolve a threat to personal abilities (Cornally & McCarthy, 2011). How and when a person decides to seek help is often influenced by their cultural values and their social network (e.g. family and friends). This is particularly true for dementia where relatives and friends, rather than health professionals, are often the first people from whom help is sought (Werner, 2003; Hodgson, Cutler, & Livingstone, 1999) and where the person with dementia may not recognise cognitive changes and symptoms (Green, Mohs, Schmeidler, Aryan & Davis, 1993). The term "lay appraisal" (Hollingshead & Redlich, 1958) is used to describe the central role families and friends play in identifying symptoms and helping to make decisions about the appropriate course of action.

In a review looking at lay perceptions in old age Werner (2005) found that there was a scarcity of empirical literature focusing upon mental health literacy (knowledge and beliefs about mental health problems; Jorm et al., 1997) associated with conditions

of older age (e.g. dementia). Where research had been conducted the focus was on labelling dementia (Werner & Davidson, 2004), relatives' concerns about developing dementia (Werner, 2003), knowledge and beliefs about the causes of dementia (Hinton & Levkoff, 1999; Ayalon & Arian, 2004) and emotional reactions to a person with dementia (Benbow & Reynolds, 2000). This gap in the literature means that little is known about how decisions to seek help for dementia are made. A further limitation of the research is the lack of a sufficient theoretical framework. Theory in health care is key as it facilitates the planning, commissioning, implementation and monitoring of interventions and health promotion (Green, 2000).

One theoretical framework that has been applied across different medical conditions including cancer (Kelly et al., 2005), diabetes (Grzywacz et al., 2011) and schizophrenia (Lobban & Barrowclough, 2005) is the Common Sense Model of Illness Representations (CSM) (Leventhal, Meyer, & Nerenz, 1980). The CSM looks to explain how individuals make sense of threats to health and the onset of illness. It is a dual processing model as it proposes that people generate both cognitive representations and emotional responses to an illness. The CSM points to five key dimensions along which perceptions of illness may differ: identity (the name given to the condition), cause, time-line, consequences and cure or control. In combination these dimensions result in a personal model of the illness, which guides help-seeking and coping as well as a person's emotional reaction.

Qualitative research with participants in the early stages of dementia by Clare, Goater and Woods (2006) and Harman and Clare (2006) has indicated that the CSM may provide a helpful way of understanding peoples' perceptions and coping. Hamilton-West, Milne, Chenery and Tilbrook (2010) expanded upon this research in a vignette based quantitative study researching the utility of the CSM for understanding lay

perceptions of dementia and predicting intentions to seek help in relation to the possible signs and symptoms of dementia. Results indicated that participants were better at identifying the cognitive symptoms of dementia than other non-cognitive symptoms (e.g. changes in mood). Where participants believed symptoms to be related to psychological difficulties they were less likely to seek professional help. This finding has important implications for help-seeking as intentions to seek help were positively associated with the label dementia, but negatively associated with the labels depression and stress, suggesting that it is the subjective experience of dementia symptoms that will influence decisions to seek help. Hamilton-West et al. (2010) advocate that further research be conducted into how intentions to seek help translate into actual help-seeking behaviour on the behalf of a relative with dementia.

Summary

The process of help-seeking for dementia is complex due to the variability in the symptoms observed, the ability of an individual to monitor changes and the influence of social and cultural factors. If people are to be encouraged to seek help, so that advanced planning and support can be initiated, it will be important for further research to focus on help-seeking for dementia. Research to date has indicated that the CSM may provide a useful framework for understanding how people make sense of early signs and symptoms and how they make decisions about whether to seek help. Current research also demonstrated that help-seeking in dementia is often instigated by the lay network (usually relatives and partners) rather than the person with dementia. In light of this research it will be important for future research to explore the illness representations of the lay network, looking in particular at how the symptoms of dementia are recognised and how this translates into actions to seek help by close relatives.

The Present Study

This study aimed to develop current understanding of the experience of help-seeking in dementia. As previous research has indicated that family members play an integral part in initiating help-seeking for dementia, this study aimed to:

- (1.) Explore close relatives' experiences of the early symptoms of dementia and how these were perceived and understood.
- (2.) Discover and gain an understanding of how relatives responded to and made sense of the early symptoms of dementia.
- (3.) To consider how participants' experiences can inform current psychological theory surrounding help-seeking.

Method

Participants

A purposive sample of 11 participants was recruited from three Alzheimer's Society support groups. Nine participants completed the study (Table 1). Participants were asked if they would like to take part in the research following a presentation by the researcher. The sample size for this project was guided by Smith et al. (2009) and comparable IPA studies (e.g. Robinson, Clare, & Evans, 2005; Harman & Clare, 2006). Participants were included if they were the relative or spouse of a person who had received a diagnosis of dementia. The mean age of participants was 70.1 years (range 48-85). Six female participants and one male participant were married to a person with dementia and two participants had a parent with dementia.

Table 1

Participant Pseudonyms and Information

| Participant name | Age | Relationship to person with dementia | Relatives' name | Number of years since diagnosis | Type of dementia |
|------------------|-----|--------------------------------------|-----------------|---------------------------------|-------------------------|
| Kath | 56 | Daughter | Elsie | 2 | Mixed dementia |
| Beryl | 85 | Wife | Jim | 2 | Vascular |
| Dot | 74 | Wife | Ted | 3 | Parkinson's & Lewy body |
| Patricia | 72 | Wife | Bob | 8 | Vascular |
| Jean | 66 | Wife | Malcolm | 4 | Alzheimer's |
| Alison | 71 | Wife | George | 6 | Alzheimer's |
| Mona | 69 | Wife | Peter | 6 | Alzheimer's |
| Emma | 48 | Daughter | Alf | 2.5 | Early onset dementia |
| Stuart | 82 | Husband | Linda | 1 | Alzheimer's |

Interpretative Phenomenological Analysis (IPA)

One of the most appropriate qualitative research methods for exploring human experience is Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009). The key theoretical perspectives of IPA are; phenomenology, interpretation (hermeneutics) and ideography (Smith et al., 2009; Smith, 1999; 2004). IPA was chosen because its phenomenological epistemology fitted with the study's aim to explore participants' subjective experiences in rich detail and because IPA is also an appropriate research method when research is concerned with 'process and complexity' (Smith & Osborn, 2003, p.53). Smith and Osborn (2003, p.51) coined the phrase 'double hermeneutic' to highlight how in IPA the interpretative process entails the interpretation of both the participant (making sense of their own experiences) and the researcher (interpreting the participants' account) (Smith et al., 2009). In this way IPA

acknowledges that the process of interpretation is complicated by the researchers own ideas and experiences (Smith et al., 1999).

Following the process of analysis, IPA seeks to consider findings in the context of existing theory. This complemented the study's aim to explore findings in light of existing psychological theory surrounding help-seeking.

Procedure

Participants were approached following a presentation at each of the Alzheimer's Society groups. If participants expressed an interest in taking part they were provided with an information sheet (Appendix B). Participants were given time to read the information sheet and to discuss their potential participation in the study with their family.

When contacted by the researcher, two participants had decided that they did not want to take part in the study due to other commitments. Those who opted to take part were asked to provide written consent (Appendix C).

Interview data was collected from nine participants who were interviewed in their own homes. The researcher debriefed participants at the end of the interviews, checking in with them to see that they were not feeling distressed and providing them with the contact details for support services where requested. Interviews lasted between 40 and 90 minutes and were audio-recorded. Interviews were transcribed by the researcher and made anonymous (using pseudonyms) prior to analysis (Table 1). On completion of the study participants were provided with a summary of the research findings (Appendix D).

Measures

Interview schedule

A semi-structured interview schedule (Appendix A) was developed in line with the study's aims. Interview questions were open-ended and covered the following topics: symptom recognition, diagnosis and the process of seeking information and support. A semi-structured design was used to allow flexibility for participants to discuss their own experiences and ideas as well as allowing scope for the researcher to ask further questions to elucidate and illuminate the subject (Patton, 2000). The interview schedule was discussed with research supervisors and staff from an Alzheimer's Society group as well as being piloted on a colleague.

Ethics

Ethical approval was attained from the Salomons Research Ethics Committee, the study complied with the BPS Code of Ethics and Conduct (2009). Particular consideration was given to issues of consent and to the possibility that the interview may cause distress to participants.

Data Analysis

Interviews were analysed using the IPA procedures set out by Smith et al. (2009). Each of the interview transcripts was examined in detail through a process of reading, re-reading and making notes on the transcripts. Initial notes were made in relation to descriptive, linguistic and conceptual comments about the data (See Appendix E for a sample transcript). Following this, the transcripts and initial notes were re-read, one at a time, and emergent themes noted down. Connections between themes were examined using spider diagrams to cluster related themes and to help

develop superordinate themes (See Appendix F for photographs of the spider diagrams). Finally, transcripts were read again to confirm that the themes were captured in the verbatim transcripts and to note down quotations to illustrate each theme.

Quality Assurance

To facilitate the process of being able to look at the research with “relative openness” (Giorgi, 1994, p.212) the researcher kept a reflexive diary (Appendix G for diary excerpts). The researcher had experience of supporting a family member with dementia and they did not want these experiences to take precedent over that of the participants. The use of a reflexive diary allowed for an awareness of pre-existing experiences and assumptions so that they could be considered separately from participants’ descriptions during data gathering and analysis (Finlay, 2009). In line with Williams and Morrow’s (2009) guidelines on achieving trustworthiness in qualitative research the themes presented are grounded in the data through the use of excerpts from the interviews. Interpretations and themes were discussed with an independent individual (somebody who did not take part in the study) who had a parent with dementia, as well as being debated with supervisors and an independent researcher.

Results

The process of analysis produced seven themes which were subsumed under three superordinate themes: ‘developing the courage to act’, ‘naming the elephant in the room’ and ‘repositioning’ (Table 2). Each of the superordinate themes and corresponding sub-themes is presented and discussed alongside illustrative quotes

from the data. The sub-themes do not represent independent concepts but form part of the concept described by the overarching superordinate theme.

Table 2.

Superordinate Themes and Sub-Themes

1.0 Superordinate Theme - Developing the Courage to Act

(sub-themes)

1.1 Unspoken fears

1.2 Assessing the risk

(Notes clustered from initial coding)

Rationalising and minimising, old age, less threatening conditions, silly behaviours

Fear of being blamed

Noticing, memory, out of character, perceptual problems, changing personality

Risk, getting lost, spilling tea, driving

Accumulation of small changes

2.0 Superordinate Theme- Naming the Elephant in the Room

(sub-themes)

2.1 Encouraging & seeking professional opinion

2.2 The importance of having a name

2.3 Reactions to diagnosis

(Notes clustered from initial coding)

Joint process

Feeling like a bully/ betrayal

Sense making

Facilitating discussion

Providing a way forwards/ sign posting what is to come

Feeling abandoned

Information overload/ overwhelming

Depressing

3.0 Superordinate Theme- Repositioning

(sub-themes)

3.1 Making interpersonal adjustments

3.2 Coping

(Notes clustered from initial coding)

Loss – of the person and the known relationship

Developing new skills

Taking on a more parental role, changing roles.

Living in the moment, humour, talking/ social support, balancing their needs and your needs.

1.0 Developing the Courage to Act

All of the interviewees described an extended period of time, prior to diagnosis and seeking professional help where they had begun to notice dementia related changes in their relative. Participants' reflected on how at first, they had tried to rationalise or minimise symptoms, but this became increasingly difficult as the symptoms and their associated risk increased. This process, where participants' gradually shifted from having unspoken concerns about their relative, to a position of feeling ready to act and confront their worst fears has been conceptualised as interviewees developing the courage to act. The sub-themes that made up this superordinate theme will now be described.

1.1 Unspoken Fears

Participants' recalled how they had first started to notice small changes in their relative including: changes in mood, perceptual difficulties and problems with short-term memory. The excerpt below is from Stuart who recalled being particularly shocked when he noticed his wife Linda, struggling to count out money. Linda had previously dealt with all of their finances.

I mean with money she has always been able to count it out, no problem, but she was counting out £3.50 here the one morning, and well, oh it took her ages and ages (Stuart)

Dot recalled how one of the first changes she noticed in her husband Ted, was his hand writing:

He had always had very good handwriting, but his handwriting got smaller and he began to forget things (Dot)

The changes noticed by interviewees raised their concerns because they were out of character and challenged their existing knowledge of their relative. Mona found the

change in her husband's temperament particularly difficult because she had always known him to be a very passive and easy-going man.

He started to get bad tempered and uh, how can I put it, not aggressive, not in the beginning anyway, but annoyed with himself (Mona)

Participants discussed how they had kept these early observations to themselves. They reflected on how they had tried to alleviate their concerns by normalising their relatives' difficulties and keeping ideas about the underlying cause of the symptoms out of mind:

Of course first of all with the memory you think, oh well, old age (Beryl)

Yeah well and then you think well she had been, you know, we thought being a bit more forgetful, old age, you know (Kath)

I suppose I wanted to believe that it was just part of the normal ageing process. I wanted to believe that this is what it was and nothing more serious, you know. (Alison)

Kath, Beryl and Alison reflect on how they had tried to view symptoms as part of the ageing process. Alison's comment was particularly poignant as she demonstrated insight into her desire to believe her husband George's difficulties were not related to something more serious (i.e. dementia). Dot also reflected on how keen she had been to avoid thoughts of dementia at the start of her husband's difficulties:

I don't think initially, when it first happened, I did not really want to know about it (Dot)

Participants' also tried to make sense of symptoms and manage their concerns, by drawing on their existing knowledge and placing symptoms in the context of previous

health problems experienced by their relatives. For example, Dot's husband Ted, was recovering from cancer when he first started to exhibit symptoms of dementia, this led Dot to try and relate his symptoms to the cancer and the aggressive treatment regime Ted had just finished.

1.2 Assessing the Risk

Interviewees discussed reaching a point where the frequency and associated risk of their relatives' symptoms had started to increase:

It is an accumulation of lots of small things. I noticed that when he was driving he was pulling to the left all the time and getting too near the curb. He would see something in front of him but it did not register quick enough for him to do anything about it (Beryl)

His balance was getting worse so he had a lot of falls and um his coordination was deteriorating (Jean)

Beryl and Jean were concerned their husbands' difficulties may result in a serious accident if they failed to do something. Another interviewee, Alison, found the courage to talk to her husband George, after he went missing whilst they were on their annual Christmas shopping trip. Alison had been concerned about George prior to their shopping trip but this event shifted her into thinking that she had to act:

Well I thought well you know it is the writing on the wall really, if I don't feel that this is significant then there is not hope for me (Alison)

In summary, this theme captures how interviewees over time and in response to the risks associated with their relatives' symptoms, developed the courage to confront their unspoken fears. The term courage is used to try and capture the bravery that

participants' needed to acknowledge their relatives' symptoms, pushing their own desires to keep hold of that person to one side.

2.0 Naming the Elephant in the Room

This superordinate theme encapsulates participants' experience as their relatives' difficulties became increasingly public and were given a name. After the process of acknowledging their relatives' difficulties, interviewees described taking an active role in trying to seek additional information and a diagnosis. Interviewees described how having a diagnosis helped them to make sense of what was happening to their relative. This period of making sense of the situation, represented a turbulent time for interviewees where they experienced a host of difficult emotions. The metaphor of naming the elephant in the room is used to capture the difficult process that interviewees faced when encouraging their relative to name and acknowledge the problem.

2.1 Encouraging and Seeking Professional Opinion

Interviewees described taking a pro-active role in encouraging their relative to seek help, whether this entailed encouraging their relative to make a GP appointment or making and attending an appointment with them:

I said well perhaps you better go and see the doctor (Dot)

Ted had insight into some of his symptoms and needed little encouragement from Dot to go to the GP. This differed from Mona's experience; she described how she and her son had to keep on at her husband Peter, so that he would make an appointment with the GP:

Well basically because we kept on to him all the time, it was not, he did not come out and sort of say well I think that I ought to go to the doctors it was us saying
(Mona)

The following excerpt is from Emma:

Well we went about something else we did, um, but I can't remember what we went for originally, I went with him and then I mentioned well I had to say that I thought it was to do with his hearing but

(Interviewer) You believed it was his hearing?

Well I did not believe it was to do with his hearing but it was my way to try and bring dad into it, not meaning to be sneaky, but you know what I mean, gentle.

(Emma)

Emma's father Alf, had been reluctant to visit the GP as he did not feel that he had a problem. This left Emma torn between wanting to get the problem addressed, and respecting her father's opinion that nothing was wrong. Emma managed this situation by asking her father to attend the GP about his hearing. She hoped that he would begin to have some insight into his difficulties. The action taken by participants' varied across the interviews but participants usually took up a more active role where their family member was not as aware of their difficulties.

Interviewees often experienced feelings of guilt for shedding light on their relatives' problems and for pushing them to get a diagnosis:

It almost felt like I was betraying him, like I was stabbing him in the back

(Emma)

While you are over there (at the GP's) they are in with you, so you can't really say too much, you know, because she does not like to think that she has got anything, you know so (Kath)

Kath's excerpt illustrates how she wanted to maintain her mother, Elsie's, self-esteem. She was aware that her mother did not recognise, or did not want to recognise that she had dementia. These excerpts reveal some of the complexity of being part of the help-seeking process.

2.2 The Importance of Having a Name

All participants stressed the importance of having a name for their family members difficulties:

I mean it is at least you know then don't you like because I mean if I had not been told I mean I suppose he would still have been acting strangely when he got home and I would still have been worried (Patricia)

I mean yes there is definitely a problem and then well if you know it is a problem then it is hopefully finding a way to deal with it (Emma)

Having a name to put to it is useful and discussing it with other people (Beryl)

The excerpts above illustrate the different reasons why interviewees felt it was important to have a diagnosis. Patricia found that having a name allowed her to make sense of her husband's behaviours, whereas Emma discussed how knowing that there was a problem and that it had a name had opened up the possibility of finding ways to help deal with the dementia.

This sub-theme demonstrates some of the factors that motivated participants to seek help.

2.3 Reactions to Diagnosis

Receiving the dementia diagnosis appeared to bring up a range of different emotions for participants. Initially participants' described feeling relieved:

Do you mean when the diagnosis was made? Ummm well a slight tinge of relief in that there was an explanation for these problems you know, slight, slight relief
(Alison)

Alison describes how her feelings of relief were related to the fact that she was provided with an explanation for George's difficulties. Alongside feelings of relief, Participants' discussed other more complex and painful emotions:

When they went on to say that he had got the dementia I think that I personally thought of really bad things, you know, of him being in a really bad way, not dressing himself or you know needing everything done (Emma)

Emma's excerpt illustrates how the dementia diagnosis brought up negative thoughts about the future and left her anxious and worrying about how her father would be in the future.

You know it was just here are your tablets and go like, you know, and you don't know which road to go down, put it that way (Mona)

After receiving her husband's diagnosis Mona seemed to have been left feeling abandoned and unsure about what to do next.

In summary, this superordinate theme has demonstrated the complexity faced by participants when seeking help with or on behalf of their relative. Whilst all of the

interviewees reported that having a diagnosis was helpful their descriptions revealed just how turbulent the help-seeking process was.

3.0 Repositioning

Across the interviews participants' talked about their relationship with their relative and how this had changed as a result of the dementia. They acknowledged the losses that they had sustained (both loss of the person and loss of their known relationship), as well as changes in their identity and roles within the relationship. The interviewees' constant efforts to adapt to their relatives difficulties has been conceptualised as 'repositioning', where participants' repositioned themselves in an attempt to integrate dementia into their lives.

3.1 Making Interpersonal Adjustments

Participants' revealed aspects of their relationship with their relative that they had started to lose or which had altered. For example, Beryl talked about her husband Jim and how he had lost the ability to coordinate his clothes:

*Yes because he always used to coordinate all his clothes himself and well
now I put them out and sometimes I have to help him put them on (Beryl)*

Beryl and the other interviewees did not get stuck on talking about the losses but instead provided examples of how they had adapted or changed their way of thinking or the things they did in order to support their relative:

*Obviously as each day goes by it becomes more restricting and you can't do as
much, so you have to learn to accept that and the fact that we can't do this but we
can do....(Dot)*

Um yes well things have changed but our way, well yeah our way of living has changed because, it is me, it is a role reversal then put it that way, what he used to do, you know all the everyday bills and things like that, it is all up to me now (Mona)

Mona and some of the other participants likened the changes in their relationship to a role reversal or taking on the role of a parent.

3.2 Coping

Alongside interpersonal adjustments interviewees reflected on the coping strategies they used to maintain as 'normal' a life as possible. Humour was important to Beryl and her husband, Jim, as a way of escaping some of the sadness and frustration that they both experienced:

We try and make it a little bit of fun if we can because otherwise you would just sit there and cry (Beryl)

Dot also found humour helpful as it helped her to maintain an emotional connection with Ted and to acknowledge the parts of him that were still in tact:

But his sense of humour, he is still in there, we well have a laugh and a joke (Dot)

Alongside humour, other coping strategies that were discussed by participants included living in the moment:

But we just have to live one day at a time and just, it is no good thinking, you can't think too far into the future it is just...you have to take it day by day (Kath)

I would say to him, I think we just have to take things day by day and cope as best we can (Jean)

Balancing each other's needs:

Ted has a befriender and then that is somebody who takes him out on a Monday just for a couple of hours. It is lovely for him to have a mans company and then it is nice for me to have a couple of hours break per week (Dot)

And talking/ social support:

But to talk to another carer, I feel like I am not coping and they will say things like, hey we all get like that, you know, and you just feel like yes and you can come from there thinking, well oh well I do not have to feel so bad anymore because it is just one of those days (Emma)

In summary, this superordinate theme has demonstrated the continual process of adjustment that participants' used to support their relative and themselves. When taken together the superordinate themes demonstrate a process that family members passed through. This process began when interviewees first recognised and came to terms (emotionally) with the fact that something was wrong with their relative, and resulted in them gradually making their concerns more public, and engaging in strategies to facilitate coping.

Discussion

The three superordinate themes: 'developing the courage to act', 'naming the elephant in the room' and 'repositioning' are connected and represent the experience of help-seeking for dementia from the perspective of close relatives. The results are now considered in relation to the original research questions and in light of existing research and theory.

How did relatives' experiences the early symptoms of dementia and how were these perceived and understood?

Interviewees recounted noticing a range of different signs and symptoms of dementia including both cognitive (e.g. short term memory) and non-cognitive (e.g. mood) symptoms. Many of the symptoms identified by interviewees were very slight, however, they stood out for them because they were out of character for their family member. These findings are similar to that of Orona (1990) who found that close relatives, such as spouses, were best placed to notice subtle, uncharacteristic behaviours that signalled the first signs of dementia. Participants found the symptoms exhibited by their relatives unsettling but frequently kept their concerns to themselves. As a means of alleviating their fears, participants described trying to normalise or deny the changes noticed. One of the ways interviewees' normalised symptoms was by attributing them to the 'normal ageing process'. This 'illness-ageing rule', where symptoms are attributed to ageing, has been demonstrated across previous dementia research (Clare, Goater, & Woods, 2006; Locher, Burgio, Goode, Roth, & Rodriguez, 2002). Whilst participants gradual response of noticing and rationalising their relatives' symptoms can be viewed as causing a delay in help-seeking, this gradual process seemed integral to participants coming to terms emotionally with the situation and having the courage to deal with it. Similar findings have been found in interview-based research with couples (Clare, 2003; West, 2003; Robinson, Clare & Evans, 2005) where couples were understood to engage in avoidance and denial as part of a cyclical process of slowly turning to face the dementia.

A key factor for participants developing the courage to act was an increase in the frequency and risk associated with their relatives' symptoms. This finding is in line with a recent review of the dementia literature, which found that 'where symptoms repeat

themselves in severity and frequency' (Prakke, 2011, p.12) it is increasingly more difficult for people to normalise or ignore them. This finding seems to link with Janis's (1958) 'emotional drive theory', which suggests that a moderate level of fear is required to prompt people into coping with an event.

How did relatives respond to the symptoms of dementia?

In keeping with the existing literature (Iliffe & Wilcock, 2005; Robinson et al., 2009; Teel & Carson, 2003) the close relatives who took part in this study were found to take an active role in seeking information and support for their relative, once they had acknowledged and begun to accept what was happening. The role taken by participants, when encouraging their family member to seek help was often dependent upon the level of insight that their relative had. Where the person with dementia demonstrated little awareness of their difficulties or was resistant to talking about them, interviewees became more involved, for example, attending the GP appointment with their relative or seeking advice on their behalf. Participants found these experiences upsetting and discussed feeling as though they had betrayed their family member by pushing them into a position of acknowledging and discussing their problems, this is something that has not been captured in much of the existing literature.

Interviewees reported that seeking help through their GP and receiving a diagnosis or name for their relatives' symptoms was helpful. Receiving a diagnosis allowed participants to make sense of their relatives' behaviours (Prakke, 2011) and facilitated the process of being able to discuss and think about ways of coping with the dementia. This finding is supported by a previous study by Baikie (2002) who found that having a dementia diagnosis enabled couples to start adjusting to changes and developing plans for the future. Alongside the sense of relief that participants' experienced as a result of having an understanding and reason for their relatives'

difficulties, participants also experienced feelings of sadness, anger and isolation. Anger was often directed at health professionals with regard to the lack of interventions offered and the absence of information available about organisations such as the Alzheimer's Society. Previous research has reported that a lack of emotional and practical support surrounding diagnosis increased feelings of isolation (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Cheston & Bender, 1999; Zarit & Edwards, 1996).

The interviewees in this study were engaged in an on-going process of repositioning themselves in response to their relative. This involved them having to take on new roles and identities within their relationship and developing coping strategies that would support them and their relative. Research on loss suggests that people have to survive the loss (the dementia diagnosis, in the case of participants in this study) and incorporate themselves into a new social identity (Harvey, 1998; Miller & Omarzu, 1998). Research by Holman and Lorig (2000) has also pointed to the importance of flexibility and constant adjustment when coping with a chronic condition. These are factors that the theme 'repositioning' encapsulates, as participants appeared to learn how to integrate their relatives' dementia into their lives, whilst maintaining as 'normal' a life as possible. The adjustments made by close relatives (carers) are key, as research by Kitwood (1997) has supported the idea that an encouraging and empathetic environment can help slow down the progression of dementia and conserve the person with dementia's sense of personhood.

How can participants' experiences inform current psychological theory surrounding help-seeking?

To date, the CSM (Leventhal et al., 1980) is the main theory to have been drawn upon in gaining an understanding of help-seeking and dementia (Clare et al., 2006;

Harman & Clare, 2006; Hamilton-West et al., 2010). The research has indicated that the CSM may offer a useful way of understanding peoples' perceptions and coping in relation to dementia.

The CSM proposes that when people try to make sense of a threat to health (their own or somebody else's), like dementia, they will form both cognitive representations (illness representations) and emotional responses to the symptoms. Both of these responses were evident in this study as interviewees responded to their relatives' symptoms by becoming concerned and fearful (emotional response) and trying to make sense of the symptoms in the context of what they knew about their relative and older people (attempts to form a cognitive illness representation). Similar to research across other health conditions, the participants in this study were not able to begin the process of seeking help, until there was an accumulation of objective features (symptoms) and risk (Johnson, 1999). In other words, it seems that as participants' emotional response (anxiety about what could be wrong) increased they found the courage to go and find out more and to begin seeking help. This is consistent with self-regulation theory, which proposes that people will be motivated to engage in common sense coping behaviours (e.g. visiting the GP) as a way of trying to self regulate their emotions and cognitions (Benyamini, 2009).

The CSM indicates that there are five dimensions along which a person's illness representation may differ: identity (symptoms and label), cause, consequences (effects on life style), time-line (time to develop and duration) and controllability. The interviewees in this study appeared to be focused on issues of illness identity, cause and consequences as they began to notice their relatives' symptoms. Illustrated by their consideration of whether symptoms were linked to old age and the assessment of symptoms with regard to their risk and frequency. Participants did not discuss thinking

about the other elements of the CSM (time-line and controllability) until they had received the dementia diagnosis. In line with previous research (Green, Payne, & Barnitt, 2004), these findings suggest that until people are provided with a clear label for their relatives' symptoms it is difficult for them to consider issues of controllability and prognosis, and to form accurate and clear cognitive representations.

Another feature of the CSM is that it is a three stage processing system. In the first stage people are thought to form emotional and cognitive responses to illness, in the second stage coping strategies are generated and in the third the coping strategies are appraised and amended. These three stages were observed in the current study as participants formed emotional and cognitive responses to their relatives symptoms (depicted by the themes: developing the courage to act and naming the elephant in the room), which led on to them developing coping strategies that were continually evaluated and amended (described by the theme: repositioning). Participants appeared to move back and forth between these stages as they acquired new information and tips from other carers.

Summary

The interviewees in this study reported being in a good position to notice the early symptoms (uncharacteristic changes) of dementia in their relative. At first, participants found that they wanted to ignore the symptoms and keep quiet, but over time, and in response to the nature of their relatives' symptoms, participants gathered the courage to face the problem with their relative. Interviewees played a key role in supporting their relative to seek a diagnosis. Acquiring a diagnosis appeared to help participants to make sense (form cognitive representations) of their relatives' difficulties.

The motivation for participants to engage in help-seeking on behalf of their relative appeared to be guided by both emotional and cognitive factors, supporting the dual processing aspect of the CSM, where both cognitive and emotional representations are conceptualised as influencing coping behaviours. Previous research has focused on the cognitive illness representations that people hold, however, for the interviewees in this study, the emotional response they experienced in relation to symptoms appeared to be the catalyst to them finding out more information and seeking help. The fact that it took participants a reasonable amount of time to speak up about their concerns is perhaps indicative of just how difficult it can be for people to face a condition like dementia.

After initiating or supporting the process of help-seeking the participants in this study made great efforts to develop coping strategies and adjust to their relatives' difficulties. This supports the idea that coping is a three stage process.

Limitations

The aim of this phenomenologically oriented study was to explore and improve understanding of human experience (Husserl, 1927) rather than to achieve generalisable results. The findings have shed light on the experiences of close relatives' regarding help-seeking and the recognition of the early signs of dementia, and will go on to indicate a number of areas where clinical practice might be improved. Nonetheless, the transferability of these findings may be limited due to participants being predominantly female and from the same area. If findings that can be generalised are to be found, demographically diverse quasi-experimental studies with a control group are needed.

The research was based upon a sample of participants recruited from the Alzheimer's Society. This meant that participants were all people who had engaged in help-seeking and who were motivated to take part. Because the aim of this study was to look at how symptoms were recognised and help-seeking initiated it was important to recruit people who were engaged in services. However, further research might seek to explore the experiences and views of family members who have not engaged with agencies for support.

Research Implications

The study's findings explicate several future research directions, including further investigation of the utility of the CSM for understanding help-seeking for dementia. Given the small scale of the current research project, a larger scale quantitative is indicated. To collect information about illness representations on a larger scale such research might look to use the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002). Data could be collected from both people with dementia and their partner (close relative) to allow for comparison of the illness representations held.

The participants' in this study indicated that they found the process of seeking help and a diagnosis for their relative distressing. Further research might look to explore the factors that would help support family members during this process. Such research is necessary to improve existing support and advice and to potentially develop new therapeutic interventions for relatives and carers. Currently interventions are often aimed at the person with dementia rather than their family.

Clinical Implications

The analysis has highlighted several areas where clinical practice might seek to make improvements. Firstly, it is important that dementia services acknowledge problem recognition and help-seeking as a joint endeavour between the person with dementia and their family. The Carers Equal Opportunities Act (2004) states that it is the responsibility of health services to provide a service to carers and family members. This is an important consideration for services when people with dementia do not want to seek help, as it is possible that their family will still be in need of support. Services might think about offering one-off consultations to family members who are concerned about a relative.

Secondly, services might seek to improve the advice and support that families are provided with post-diagnosis, this might enable them to feel supported and contained. This could be achieved through services such as memory clinics and, services for older people sign-posting or working alongside relevant external agencies (e.g. the Alzheimer's Society & Admiral Nurses) to provide psychological support. There is also an argument for services to push for greater input from clinical psychologists and counsellors so that greater psychological support can be provided for family members as part of a post-diagnostic package. This is particularly important given the negative effects that long-term dementia caregiving can have upon family members (Brodaty, Thompson, Thompson, & Fine, 2005; Gerber & Banks, 2002).

Lastly, this study showed that the CSM provided a relevant theoretical framework for understanding how family members seek help. If the lay population is expected to hold more accurate illness representations about dementia it may be helpful to draw upon the five dimensions of the CSM when designing posters or ad-campaigns to promote help-seeking. This would ensure that a full and clear description

of dementia is provided. The CSM has been found to provide a useful framework for health promotion campaigns across other health conditions (Johnson, 1999).

Conclusion

This is one of the first qualitative studies to explore close relatives experiences of symptom recognition and seeking help in relation to the early signs of dementia. Results indicated that participants observed both cognitive and non-cognitive symptoms in their relative. Participants' motivation to engage in help-seeking on behalf of their relative was guided by emotional and cognitive factors, supporting the dual processing aspect of the CSM where both cognitive and emotional representations are conceptualised as influencing coping behaviours. Future research and clinical directions have been highlighted and it is hoped that these will further contribute to the theoretical understanding of help-seeking for dementia.

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**Section C:
Critical Appraisal**

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1.0 What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?

Prior to undertaking this study my main research experience had come from completing audit and evaluation projects as an assistant psychologist, and carrying out small-scale research projects at undergraduate and Master's level. Whilst these experiences had provided a good introduction to research methods and conducting research, I feel this project has helped me to develop a number of new research skills including the ability to develop a research proposal, seek ethical approval, liaise with different organisations and to juggle the demands of completing a piece of research alongside other commitments. All of these skills will help to boost my confidence when planning and undertaking research in my first job, post-qualification.

When starting my research I felt really anxious about making contact with the Alzheimer's Society (AS) support groups and beginning the process of recruitment. The AS members of staff were, understandably, very cautious about allowing me to meet with and present my research to their group members. This left me feeling very aware of the need to respect their organisation and ways of working, as well as the need to maintain a very professional relationship. Despite initial anxieties I was able to develop a really positive relationship with the AS staff, which was demonstrated by their support in helping me with my research and the positive feedback they gave me. I feel that these experiences have been incredibly valuable, as they have provided me with skills that I can take forward when completing research in the future and when working clinically with external agencies and organisations.

When conducting research previously I have not dedicated time to acknowledging my own assumptions and preconceptions as I did with this project. I found having space to reflect particularly important as it allowed me to think back on my own family's experiences when my grandmother developed Alzheimer's disease. I do not think that it would have been possible or desirable to bracket or deny my own experiences and understandings surrounding dementia (Halling, Leifer, & Rowe, 2006), but it was helpful to take the time to bring them to the fore, so that I was more conscious of them when conducting the research. This is something that I will continue to do when conducting research in the future.

Completing my project helped me to build upon my qualitative research skills. I have not used Interpretative Phenomenological Analysis (IPA) before and so it helped me to learn about what it means to carry out research from a phenomenological epistemology. I feel that IPA was a suitable research methodology for conducting the project, as it was important to try and capture the richness of participants' descriptions (Finlay, 2009). Nonetheless, conducting the interviews at times proved difficult when participants gave brief descriptive answers and struggled to talk more openly about their experiences. Prior to doing the interviews I had practised going through the questions and generated a list of prompts. Although this preparation proved to be helpful I feel that conducting interviews is something that I need continued practice at, particularly with regard to asking questions that get at the meaning of participants' experiences (Smith, Flowers, & Larkin, 2009). Another area where I would like to develop my ability is the analysis of qualitative data. Whilst I enjoyed the process of reading through the transcripts, developing themes and then looking for themes across the transcripts, I found it a challenge to know whether I was meeting the level of analysis and interpretation that IPA encourages (Larkin, Watts, & Clifton, 2006). Giorgio

(1997) discussed how the method entails three steps: phenomenological reduction, description and the search for essences. It is the search for “essences” and revealing the meaning behind participants’ accounts that I found most challenging. Smith et al. (2009) recommend conducting research with fewer participants as a way of honing analytic skills and this is definitely something that I would consider trying in the future.

2.0 If you were able to do this project again, what would you do differently and why?

Initially when designing the research project I had planned to use a mixed methods design similar to that of Harman and Clare (2006), where they combined IPA with a theory driven content analysis. I had hoped to do this as a means of being able to address second-order research questions about the utility of the Common Sense Model of Illness Representations in greater detail. However, following discussions about my research proposal it was agreed that the two approaches would not be compatible, due to the fact that content analysis requires a larger participant sample than IPA and IPA is wedded to a phenomenological epistemology. If I were able to do this research project again I would consider adopting a research method such as thematic analysis, which would have provided greater flexibility with regard to completing the content analysis given that it is not linked to a phenomenological epistemology like IPA (Braun & Clarke, 2006).

Recruiting participants at the Alzheimer’s Society support groups meant that people who took part in the study had often been living with their relative’s diagnosis for a number of years. During the interviews this meant that it was sometimes difficult for participants to recollect the time leading up to their relatives diagnosis. In retrospect it might have been helpful to approach local memory services to ask about the

possibility of recruiting participants whose relatives had received a diagnosis more recently, although, I am sceptical as to whether people would have been able to talk about their experiences in rich detail if they were still at a point of coming to terms with the diagnosis. This had been a problem when interviewing Stuart whose wife Linda had only received her diagnosis a year earlier. Another way to address the difficulty of participants finding it hard to recollect their experiences would have been to use a first interview as a prompt for further discussion and exploration at a second interview (Smith et al., 2009). I think that this may have been a helpful approach as the interviews stirred up a lot of memories and emotions for participants, which could have been discussed further if there had been a second interview.

2.0 Clinically, as a consequence of doing this study, would you do anything differently and why?

Individual Work - When working in services for older people I have found that the work being done has often focused upon the individual with the diagnosis. Through conducting this study I am more aware of the importance of working with families, providing assessment and intervention for them alongside the person with dementia. Reviewing the dementia literature and speaking to participants helped me to see just how integral the family network were for maintaining the quality of life and independence of the person with dementia. I have also seen just how difficult it can be for relatives to consider and articulate their own needs due to the responsibility they feel for looking after their loved one. When working with individuals in the future I intend to make more of an effort to ask them about their family and to find out whether their family's needs are being met. I would also take time to discuss support needs

carefully when carrying out carer's assessments or working with a family member, to ensure that they were able to consider their needs fully.

The project has also made me question how I deliver information to clients, especially when delivering more complex information (e.g. the results of a neuropsychological assessment). In the future I will ensure that I spend longer checking out what people have understood from the information I have delivered. When discussing dementia with clients I think that I would also hold the common sense model of illness representations in mind, as I believe that the five dimensions (identity, cause, time-line, consequences, curability) provide a useful framework for ensuring that the diagnosis is discussed in full.

Work at a Service Level – My research has made me feel more passionate about representing the needs of carers within services, especially as it makes both financial and practical sense for services to provide information and support to carers, given the level of support they provide for relatives. Benefits include the prevention of deterioration in the physical and mental health of carers, as well as a reduction in future crises and care home admission for the person with dementia. Participants in this study did not have the expectation that the National Health Service (NHS) should provide all of their support but there was an expectation that services should sign-post relevant external charities and agencies for support. In this respect I would try to ensure that services where I work in the future have a good knowledge of local organisations like the Alzheimer's Society.

4.0 If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?

Conducting this research project has led me to consider a couple of different possibilities for future research projects. Firstly, I feel that there is scope for the current research project to be developed further through conducting a quantitative research project which looks at the utility of the CSM for understanding help-seeking for dementia. Alternatively further qualitative research might seek to look at the multiple perspectives on help-seeking for dementia. For example, the experiences and illness representations of people with dementia, their relatives and health professionals could be explored. This type of data would provide a wealth of information about the different beliefs that these groups may hold and the varied factors that have influenced their beliefs. Research interviews or focus groups could be used to collect this kind of data.

Secondly, based on participants' descriptions of the emotional stress and isolation that follows a diagnosis, I feel that another area for further research would be the development of group therapeutic interventions for family caregivers or couples (i.e. the person with dementia and their partner). The interventions that are currently delivered by memory services (e.g. reminiscence therapy and cognitive stimulation groups) tend to have a very practical focus and are designed primarily for the person with dementia. There seems to be a real need for interventions that include family members and carers and which are focused at a more psychological or emotional level. The development of such interventions would require careful evaluation through quantitative (e.g. self report measures) and qualitative (e.g. focus group) means, to see if they could help to reduce psychological distress and have a positive effect on the wellbeing of the patient and their partner/ family member.

Lastly, I would consider investigating the relationship between illness representations and help-seeking behaviours further. Whilst my study, and research to date, indicate that the common sense model of illness representations may be a helpful framework for conceptualising how people (both the person with the diagnosis and relatives) make sense of a health threat like dementia, little is known about the relationship between illness representations and help-seeking. For example, it is still not known whether it is the illness representations that people hold that influences their decision to take action and seek help. In order to investigate the relationship further a large-scale quantitative study, similar to the design of Hamilton-West, Milne, Chenery and Tilbrook (2010) could be conducted. Through collecting data from both people with dementia and their close relatives it would also be possible to investigate any similarities or differences in the illness representations that are held.

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Section D

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Appendix A

Semi-structured interview schedule

Introduction

Thank you for agreeing to be interviewed for this research. You will notice me taking an audio recording of our interview today, this is just so that I have an accurate record of what has been said. When I write up the interviews I shall remove any identifying features so that the information you provide will be anonymous. I would also like to remind you of your right to withdraw your data from the research at any time. If you need a break or would like to stop please just let me know.

We are interested in finding out how people identify the early signs and symptoms of dementia and what prompts them to seek professional help. This interview will be focused on your experiences as a [spouse/relative] of a person with a diagnosis of dementia.

To begin with, I would like to ask you to think back to when you first realised that something was wrong. It doesn't matter whether you realised that X had dementia at that point. Could you take a moment to think about the time before X was diagnosed? When you are ready, I'd like to ask you a few questions about what was happening.

1. Looking back what was your experience at that time?

PROMPTS

What did you notice?

What did you think was happening?

2. What did you do?

PROMPTS

Did you talk to X about what was happening?

Did you talk to anyone else about what was happening?

Did it cross your mind at this point that X could have 'diagnosis'? (Why?)

Was there anything else you thought might be causing these changes? (Why?)

Did you think that these problems would improve over time, or did you think they would stay the same or get worse?

Did you think the problem might go away by itself?

3. What did you know about dementia at that time?

PROMPTS

At what point did you suspect that X might have dementia?

Did you talk to X about your concerns?

Did you talk to anyone else about your concerns?

4. What were your experiences around seeking help?

PROMPTS

What prompted X to seek professional help?

How was the decision to seek help made?

What did the process of seeking a diagnosis involve?

5. What were your experiences around the diagnosis?

PROMPTS

Did you expect that X would be diagnosed with dementia?

How did you feel when X was diagnosed?

How was it to have a label for the problems X was experiencing?

6. What have your experiences been since X received the diagnosis?

PROMPTS

How have things changed for both since having a diagnosis?
 Has having a diagnosis improved things in any way?
 Have there been any negative aspects to having a diagnosis?

7. Have you spoken to anybody or received any information about the diagnosis?

PROMPTS

How has it been to talk to somebody about the diagnosis?
 Has the information you have received been useful?
 What did you know about treatment before the diagnosis?
 Did you believe that X diagnosis would be cured?
 What do you know now about how to treat and control the diagnosis?

8. Have there been things that have helped you both deal with the diagnosis?

PROMPTS

Medication, family support, prayer?

9. Is there anything that I have not asked about that you feel it is important to mention?

Debrief- To check in with the participant to see how they are feeling following the interview.
 Provision of any contact/ advice around further information or support.

Appendix B
Participant information sheet

The early stages of dementia: an exploration of close relatives experiences of symptoms and diagnosis

You are invited to take part in the above research project. It is important that you understand the aims of the research and what will be involved so please take time to read the following information and to decide if you would like to take part. If there is anything that is not clear or you have got any questions please just ask.

- **Who is conducting this research?**

My name is Clare Maddocks and I am a student with Canterbury Christchurch University. I am completing this research project as part of my doctoral qualification in clinical psychology.

- **What are the aims of this research project?**

To explore the experiences of family members/spouse of those who have been diagnosed within the last 18 months as being in the early stages of dementia. Specifically looking at how the early signs of dementia are recognised and how information and resources are sought.

- **What is entailed?**

Participants will be asked to take part in an individual interview lasting approximately 60 minutes.

- **Do I have to take part in this research?**

No, participation in this research project is voluntary. Should you decide to take part in this research project you will still have the right to withdraw from the research at a later date without explanation.

- **What next?**

If you would like to take part in the research project, please get in touch with the researcher (contact details overleaf). You will be provided with a consent form to sign. The research involves a single individual interview and if you would like to participate I shall contact you by telephone to arrange a time and location suitable to your needs.

The interview questions will focus on your experiences with your family member/partner who has been diagnosed with dementia, including questions about the recognition of symptoms and the process of seeking information and resources. Due to the sensitive nature of the research topic, the content of the interview may be upsetting. Contact details and advice about further information or support will be available from the researcher.

- **Why is this research important?**

It is hoped that this research will provide a greater understanding of the experiences of family members/spouse of people with dementia as well providing information on how these experiences have impacted upon decisions to seek a diagnosis/information.

- **What happens to the interview data?**

The individual interviews will be audio taped to provide an accurate record of what was said. These audio recordings will be kept securely in a locked cupboard and destroyed on completion of the research project.

A write up of the research will be available from September 2012, this write up may be published in a research journal. The write up will not include any personal information that may identify you.

- **How do I contact you?**

If you would like to get in contact to express and interest in taking part in the research, or you have any further questions, please contact me on,

Tel: ***** Email: *****

Alternatively please complete the reply slip below and return using the pre-paid envelope. I shall then contact you via telephone.

Thank you for taking the time to read this information.

Clare Maddocks
Trainee Psychologist
Salomons

TEAR OFF

TEAR OFF

Title:..... First Name:..... Surname:.....

I am interested in finding out more information about this research. Please contact me on the following telephone number.

Telephone

Number:.....

Appendix C
Consent Form

Participant Consent Form

- I have read the information sheet provided and had opportunity to ask any questions.
- I understand that I am being asked to participate in a one off interview that will be audio recorded.
- I understand that I am able to withdraw my consent for taking part in this research at any time. If I decide to withdraw from the study I do not have to give a reason and any information that I have provided will be withdrawn.
- I am aware that due to the sensitive nature of the research topic, the content of the interview may be emotionally upsetting.

I give my consent to take part in an individual interview as part of this research study.

(Please fill out in BLOCK CAPITALS)

Name: _____

Address: _____

Telephone/Contact Number: _____

Signature:

Once completed please return this form to the researcher or return in the pre-paid envelope provided. Thank you.

Researcher address:
Clare Maddocks
Trainee Psychologist
Salomons, Broom Hill,
Tunbridge Wells
TN3 0TG

Appendix D

Participant feedback: Summary of research findings

Background- It is estimated that there are 800,000 people living with dementia in the UK, a figure that is set to rise to over a million by 2021 (Alzheimer's Society, 2012). Therefore, there is a growing need for services to have a clear understanding of how the first signs and symptoms of dementia are recognised and to know how best to support the person with dementia and their family. Critically it is the early stages of dementia where there is opportunity for interventions that may have an affect on the quality of life of the person with dementia and their family (Milne, 2010). Interventions can include the implementation of support strategies that will help the person maintain their independence (Alzheimer's Society, 2010), plan for future care needs (Woods & Pratt, 2005) and make financial and legal plans (e.g. lasting power of attorney) (Milne & Wilkinson, 2002). Early diagnosis and intervention are key aims of the Department of Health's (DoH) National Dementia Strategy (NDS) (DoH, 2009). In spite of the growing support for early diagnosis it is estimated that only 43% of people with dementia in the UK have a diagnosis (Alzheimer's Society, 2012). The symptoms of dementia are often missed or attributed to other causes (e.g. ageing, anxiety and depression) and where help is sought it can often be at the advanced stages of the condition (Boise, Camicioli, Morgan, Rose & Congleton, 1999) where less can be done to support the individual and their family.

Current study- The current study explored close relatives experiences of noticing the symptoms of dementia and seeking help. The aim was to gain a better understanding of how families move from a position of noticing symptoms to one of seeking help.

Findings- The analysis demonstrated that identifying the symptoms of dementia in a relative (family member) and seeking help, was anything but a straightforward process. The analysis suggested that relatives were engaged in a complex process of: noticing changes, tackling their emotional desires to ignore symptoms and negotiating and taking on responsibility for intervention and seeking help.

One of the most salient findings to come out of the research was the fact that relatives reported a process of needing to come to terms emotionally with the symptoms of dementia before moving to a position of being able to talk about them and encouraging their loved one to seek help and information. This demonstrated that the process of help-seeking entailed more than just observing changes in their relative.

A further key finding was the emotional burden that relatives discussed in relation to encouraging the person with dementia to seek help, it was reported to bring up feelings of guilt and betrayal. Relatives described the lack of support that they had received, post diagnosis, from NHS services, which had left them feeling isolated and completely responsible for the person with dementia. Relatives reported taking seeking additional support into their own hands through contacting organisations like the Alzheimer's Society.

Implications- The analysis highlighted several areas where clinical practice might seek to make changes. Firstly it is important that dementia services acknowledge that problem recognition and help seeking is a joint endeavour between the person with dementia and their family. Whilst this has begun to be addressed in public health campaigns for dementia it is important that services provide information to family members who have concerns about a relative. Secondly services should seek to improve the advice and support that families are provided with post diagnosis, so that they feel supported and contained in their transition to becoming a carer. This will require services such as memory clinics and services for older people sign-posting relevant external agencies (e.g. the Alzheimer's Society & Admiral Nurses) and helping families to link up with these agencies. There is an argument for services to have greater input from clinical psychologists and counsellors so that greater psychological support can be provided for family members as part of a post diagnostic package. This is particularly important given the negative effects that caregiving can have upon family members

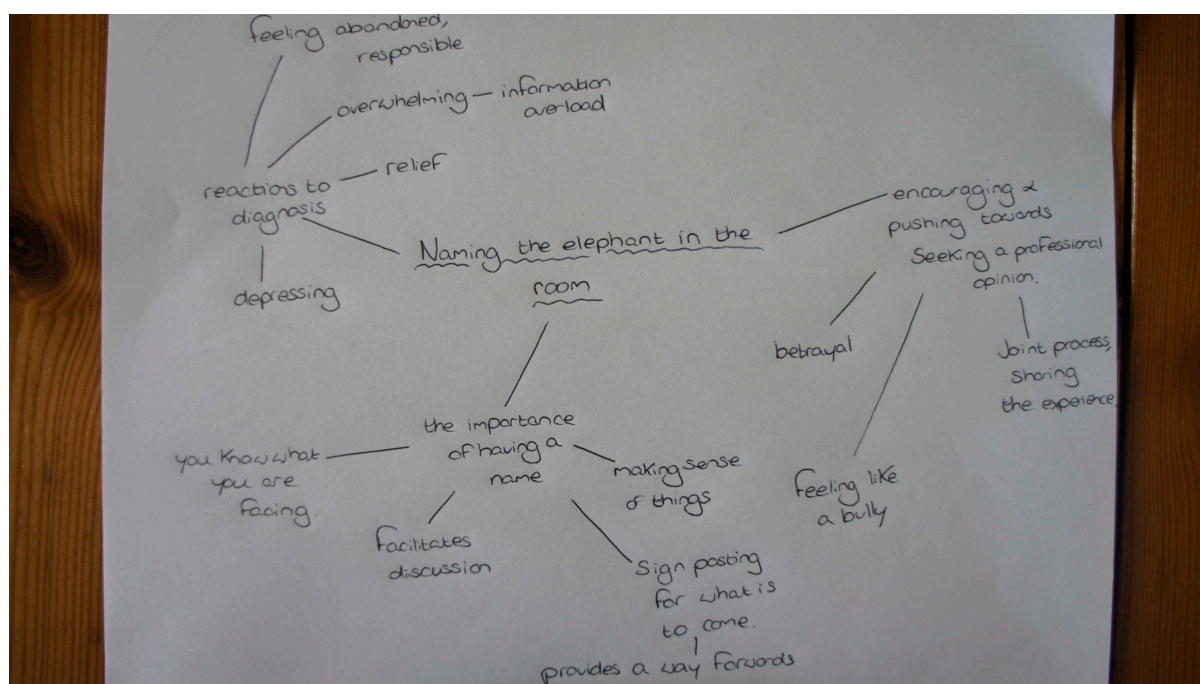
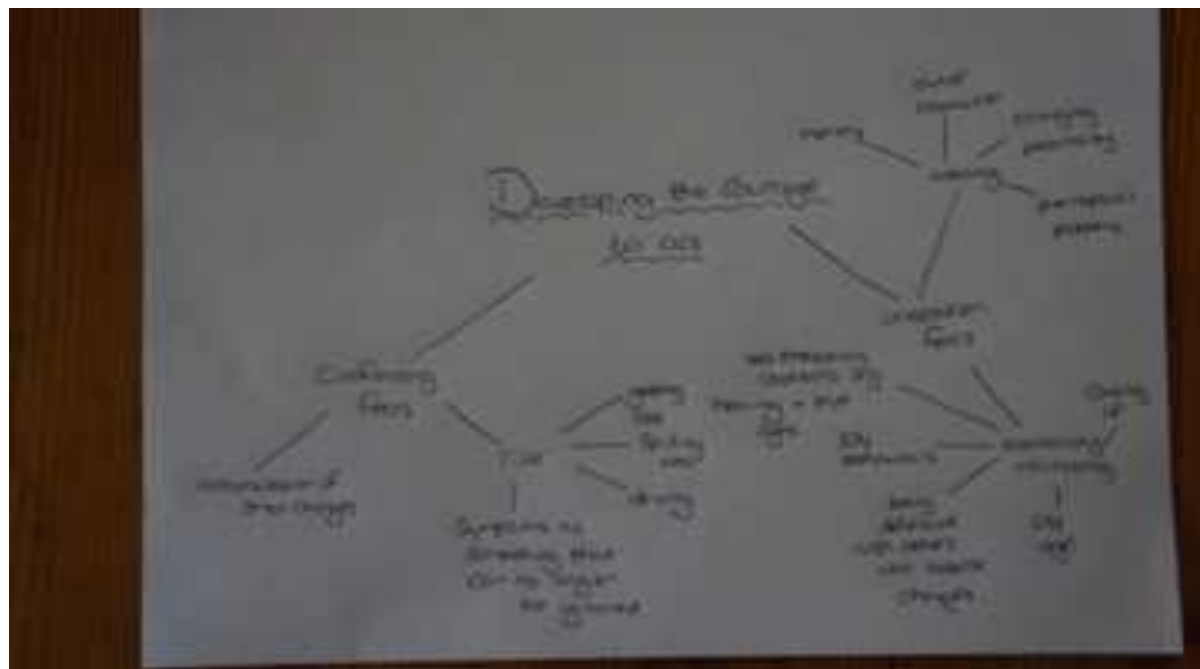
Appendix E

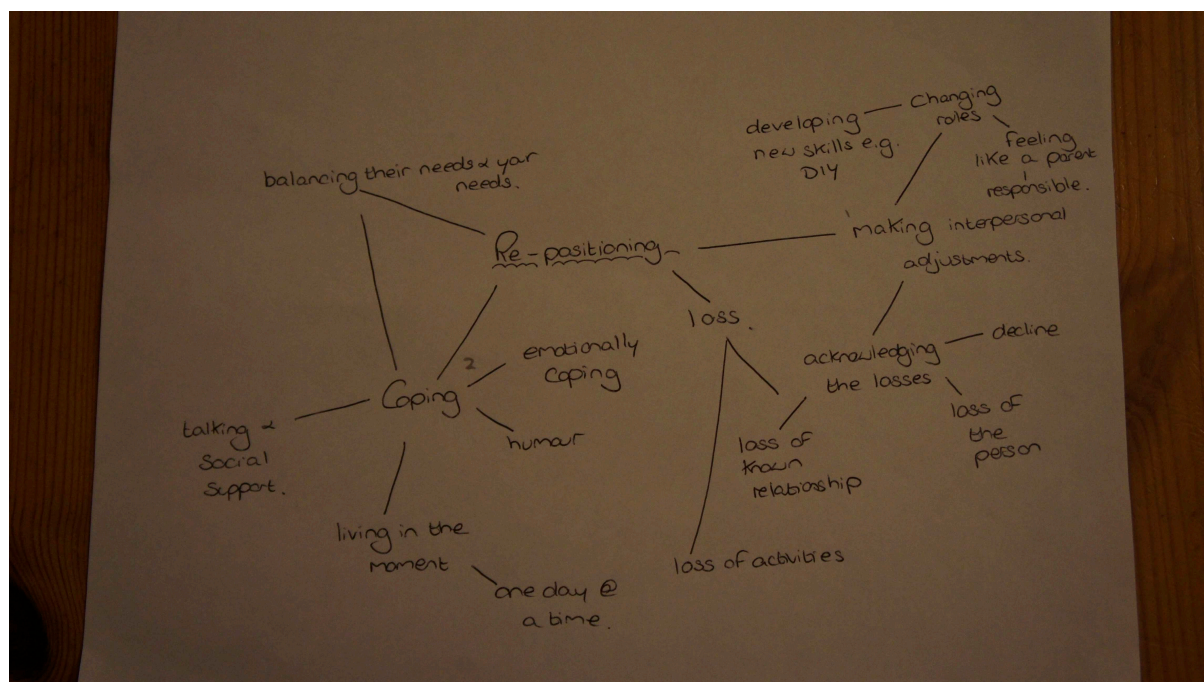
Sample transcript

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Appendix F

Photographs of Spider Diagrams Used For Analysis





Appendix G

Excerpts from research diary

22nd February 2010 – First meeting with external supervisors

Really helpful to meet up and discuss research ideas. Supervisors discussed the possibility of doing a mixed methods design similar to that of Harman and Clare (2006). Need to do read up on Harman and Clare's methodology and also start doing reading re. common sense model and dementia. Supervisors let me know that they will be able to help with: recommending research literature to read, talking through issues relating to health psychology models and dementia and reading through drafts of my research project. They are not able to help with regard to contacts for recruitment but suggested that charitable organisations and the Alzheimer's Society might be a good starting place.

15th October 2010 – MRP Review meeting

Meeting with tutors at Salomons to review my project proposal. Tutors discussed their concerns regarding my rationale for carrying out IPA and content analysis. Difficult to do both because a content analysis would need more participants than an IPA project, it is also difficult to combine IPA and a content analysis because IPA is wedded to a phenomenological epistemology whereas content analysis would be theory driven. I think at this point it might be worth considering changing to just doing an IPA study, rather than getting into difficulties at a later point.

March 2011- (Contacting Alzheimer's groups and making contacts re. recruitment).

Beginning of March- Ethical approval granted, I can now start making contacts re. recruitment.

Middle of March - Sent out around 30 emails to make contact with local Alzheimer's Society Branches, so far I have only had a reply from two groups who said that they could not help me. Staff seem very cautious and unsure about me speaking to group members and asking them whether they would like to take part. One member of staff suggested that I could put up a poster at their group, I do not think I will do that at this point as I do not think it will be as successful as meeting with people. One of the groups were also already involved in helping somebody else with a research project, this makes me worry that perhaps people who attend these groups may feel over-researched.

End of March- I have now had two emails from Alzheimer's Society groups who would be happy to help me with my project. They suggested that I attend an Alzheimer's café group to present my research to the group and ask people whether they would be interested in taking part.

April 2011- (Presentation at Alzheimer's café)

Attended the Alzheimer's Café today, felt very nervous before hand, however, it seemed to go well and the group were really welcoming. People were interested in my research and had questions to ask me. I am really struck by how passionate the people at the café were about taking part in research and making sure that the needs of people with dementia and their carers are represented. Four people expressed an interest in taking part in my research and took away an information sheet, I need to get in touch with them over the next few days to see if they are still interested in taking part.

I sat by one lady in the group who had a diagnosis of Alzheimer's disease, she seemed to think that she was there as a carer for other people in the group and quickly forgot the things that she had spoken to me about. Despite her cognitive difficulties she expressed a real interest in my research and asked questions about it. I really appreciated that people at the group should take such an interest in my research and that they have also offered their time to take part. I really want to make a good job of completing the project so that I can honour their time and effort.

June 2011- (Completion of two interviews)

I have conducted two interviews over the weekend. The two ladies seemed to be at very different stages in accepting their partner's diagnoses, although they both spoke about similar issues e.g. the need to live in the moment. The one lady became quite upset during the interview, she seemed very angry about the diagnosis and discussed how she has never really got to a point where she wants to acknowledge or accept the diagnosis.

January 2012- (Analysis)

Meeting with internal supervisor, discussed my analysis so far and the comments and ideas that I have noted down. Supervisor commented that I may be focusing my analysis at a very descriptive level and asked me some questions about the data to try and get me to think about the meanings behind the data. Plan to take a step backwards and read through my initial notes again before trying to move to a point of generating overarching themes.

March 2012- (Contact from another Alzheimer's Society)

Received an email from a lady who runs an Alzheimer's Society branch, they had not picked up my email until now. They are happy to help me with my project, I am a bit concerned that it is too late in the day to be completing further interviews, however, I would like to try and recruit 10 participants as I set out to do at the beginning.

May 2012 – (Meeting with external supervisors)

Met with external supervisors, discussed difficulties I have had in trying to improve and get section A to flow well. They have helped me to feel a bit more positive about things as they shared some of their own experiences of structuring papers and trying to use concise language. I was also able to talk through my data and let them know about the different things that people had discussed. This has really helped me to consolidate things in my mind and helped me to see some of the main tensions that participants were trying to get across to me

Appendix H

Submission details for the journal – Qualitative Health Research

The Guidelines covers matters of QHR journal style, which are not subject to author preference; adherence is required.

IMPORTANT CONSIDERATIONS

- * Qualitative Health Research is a peer-reviewed journal. Only complete, finished manuscripts should be submitted for consideration.
- * We do not publish stand-alone abstracts, quantitative studies, manuscript outlines, pilot studies, manuscripts-in-progress, letters of inquiry, or literature reviews. Research articles must be pertinent to health.
- * Write both the abstract and the text of your manuscript in first-person, active voice.
- * For best results, review this entire document prior to preparing and submitting your manuscript.
- * Proper manuscript preparation will speed the peer-review process for your manuscript, and will facilitate a smoother production process if it should be selected for publication.
- * Improper manuscript preparation could result in burdensome revisions, lengthy delays in the review and production processes, and the possible rejection of your manuscript.

GENERAL STYLE

We ask authors considering submission to QHR to review these guidelines, survey several issues of the journal, and make their own decision regarding the “fit” of their article for QHR’s mission. Please refrain from writing or calling to ask if we are interested in your particular manuscript or idea. In general, QHR adheres to the requirements of Sage Publications, Inc., and the guidelines contained in the Publication Manual of the American Psychological Association [“APA”], 6th edition (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10:1-4338-0562, spiral bound), with regard to manuscript preparation and formatting. Elsewhere in these Guidelines this book is referred to as the APA Publication Manual, or just APA. Additional help may be found online at <http://www.apa.org/>, or search the Internet for “APA format.” Many universities and private organizations have Web sites devoted to APA style. However, when guidelines found on those sites, or in the APA Publication Manual, conflict with QHR Guidelines, you must follow the QHR Guidelines.

CONFIDENTIALITY AND PROTECTION OF IDENTITY

QHR is committed to protecting the identity and confidentiality of research study participants. With the exception of participatory action research (PAR), no information that could potentially allow identification of a participant—or even a specific study site—should be included in a submitted manuscript or, subsequently, included in a published article. If the use of participant names is absolutely necessary for reader understanding, each study participant referred to in the manuscript should be assigned a pseudonym. Study sites, such as hospitals, clinics, or other organizations, should not be named, but instead should be described; for example: “Study participants were recruited from the coronary care unit of a large metropolitan hospital on the eastern seaboard of the United States.” Authors who include participant names and/or photos/images in which individuals are identifiable must submit written permission from the participants to do so—no exceptions. Permission to use photographs should contain the following verbiage: “Permission is granted to use, reproduce, and distribute the likeness/photograph(s) in all media (print and electronic) throughout the world in all languages.” To protect author anonymity during the review process, author citations in the text should include only the word “Author” and the year: (Author, 2008). Author references in the reference list should also include only the word “Author” and the year: Author. (2008). (See the section on references for more details.

Appendix I

End of study letter to Salomons ethics panel

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Appendix J

Letter of ethical approval from Salomons ethics panel

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